The New York Times
nytimes.com

May 15, 2006

OP-ED CONTRIBUTOR

Death's Waiting List

By Sally Satel

Correction Appended

Washington

MARCH was National Kidney Month. I did my part: I got a new one. My good fortune, alas, does not befall nearly enough people, and the federal government deserves much of the blame.

Today 70,000 Americans are waiting for kidneys, according to the United Network for Organ Sharing, which maintains the national waiting list. Last year, roughly 16,000 people received one (about 40 percent are from living donors, the others from cadavers). More are waiting for livers, hearts and lungs, which mostly come from deceased donors, bringing the total to about 92,000. In big cities, where the ratio of acceptable organs to needy patients is worst, the wait is five to eight years and is expected to double by 2010. Someone on the organ list dies every 90 minutes. Tick. Tick. Tick.

Until my donor came forward, I was desperate. I had been on the list only for a year and was about to start dialysis. I had joined a Web site, MatchingDonors.com, and found a man willing to give me one of his kidneys, but he fell through. I wished for a Sears organ catalog so I could find a well-matched kidney and send in my check. I wondered about going overseas to become a "transplant tourist," but getting a black market organ seemed too risky.

Paradoxically, our nation's organ policy is governed by a tenet that closes off a large supply of potential organs — the notion that organs from any donor, deceased or living, must be given freely. The 1984 National Organ Transplantation Act makes it illegal for anyone to sell or acquire an organ for "valuable consideration."

In polls, only 30 percent to 40 percent of Americans say they have designated themselves as donors on their driver's licenses or on state-run donor registries. As for the remainder, the decision to donate will fall to their families who are as likely as not to deny the hospital's request. In any event, only a small number of bodies of the recently deceased, perhaps 13,000 a year, possess organs healthy enough for transplanting.

The verdict is in: relying solely on altruism is not enough. Charities rely on volunteers to help carry out their good works but they also need paid staff. If we really want to increase the supply of organs, we need to try incentives — financial and otherwise.

Many transplant experts recognize this, proposing initiatives that would allow people to give their organs in exchange for tax breaks, guaranteed health insurance, college scholarships for their children, deposits in their retirement accounts, and so on. Ethics committees of United Network for Organ Sharing, the American Society of Transplant Surgeons and the World Transplant Congress, along with the President's Council on Bioethics and others, have begun discussing the virtues of such incentives.

Against this backdrop of mounting frustration, the Institute of Medicine, part of the National Academy of Sciences, this month issued a report titled, "Organ Donation: Opportunities for Action." Unfortunately, the report more properly should be subtitled "Recommendations for Inaction."

Basically, it recommended only one new initiative: expanding donor eligibility to patients who died of cardiac arrest. (Organs now can be retrieved only from those who suffer brain death.) This makes sense, as more people die because their heart stops than because of brain damage.

But even so, this new supply will fall far short of need. At the very least, the report should have shown enthusiasm for other initiatives. One is the popular and effective European practice of "presumed consent" in which citizens are considered donors at death unless they sign an anti-donor (or opt-out) card.

Another possibility it could have recommended was pilot studies using incentives in a regulated market. One model resembles a "futures" market in cadaver organs. A potential donor could receive compensation — outright payment, a sizable contribution to a charity of his choice or lifetime health insurance — in installments before death or to his estate afterwards in exchange for permission to recover his organs at death.

Why so timid? The Institute of Medicine cautioned against treating the body as if it were "for sale." But that's outdated thinking: we've accepted markets for human eggs, sperm and surrogate mothers. A recent poll by researchers in Pennsylvania found that 59 percent of respondents favored the general idea of incentives, with 53 percent saying direct payments would be acceptable.

Some critics worry that compensation for kidney donation by the living would be most attractive to the poor and hence exploit them. But if it were government-regulated we could ensure that donors would receive education about their choices, undergo careful medical and psychological screening and receive quality follow-up care. We could even make a donation option that favors the well-off by rewarding donors with a tax credit. Besides, how is it unfair to poor people if compensation enhances their quality of life?

Paying for organs, from the living or deceased, may seem distasteful. But a system with safeguards, begun as a pilot to resolve ethical and practical aspects, is surely preferable to the status quo that allows thousands to die each year. As the International Forum for Transplant Ethics put it: "The well-known shortage of kidneys for transplantation causes much suffering and death. If we are to deny treatment to the suffering and dying, we need better reasons than our own feelings of disgust."

Correction

This Op-Ed article originally misstated the frequency with which Americans on the transplant waiting list die. It is one death every 90 minutes, not every 90 seconds.

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